

CANCER REGISTRY AND CANCER REGISTRY CENTERS

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I. What is Cancer Registry?

All efforts made to collect data on the cancer cases in the society are called **cancer registry**. Hospitals, clinics, laboratories, oncology centers, diagnosis centers and other medical units may be the sources of the collected data. In addition, death registrations, forensic medicine records, records of the health insurance institutions or special researches and screening programs may be considered to be sources of information about cancer cases. Within the framework of these studies both the data on the diagnosis given to the patient and on the method of diagnosing as well as about the cancer patient are compiled. Data collection may be carried out at hospital and clinic level or a province, district or the whole country may be defined as the area of responsibility of the cancer registry center.

Being defined as a systematic process of continuous data collection about the development, characteristics and outcomes of cancer with a view to estimating and controlling the effects of the malign diseases on the public, cancer registry is a field of activity which is included into the health services title, which uses various scientific means and which is conducted through cooperation with particular scientific disciplines.

Cancer registry is the beginning point of cancer control. It is necessary to establish the right goals and to choose effective means in order to plan and perform efficiently the cancer control activities in a society, no matter how big it is. In order to do this, it is compulsory to obtain certain information such as the frequency of cancer, risk levels of certain cohorts, and prevalence, incidence and mortality rates of cancer groups. Performance of a scientific and systematic cancer registry is the primary condition of calculating these rates and compiling relevant information.

II. Why Cancer Registry?

This issue shall be mentioned in details in the section titled “Areas of Usage of Cancer Registry” (Section IV). However, we can summarize the basic functions of cancer registry as follows: Cancer registry is conducted for:

- The determination of the potential etiological factors,
- Establishment of the regional requirements (staff, devices and equipment, organizations, screening programs, etc); ensuring the planning and organizing the distribution of the sources,
- Development of effective primary and secondary cancer prevention programs,
- Evaluation of the executed services and implemented programs,
- Analysis of the effectiveness of different treatment approaches and their effect on the quality of life.

III. History of Cancer Registration and International Organizations

Mortality data were predominantly used in the cancer-related statistical studies made in Europe in the 18th and 19th Centuries. The first efforts of data collection on cancer patients started in Germany and United Kingdom in the early 1900s. Then respectively, the Netherlands, Spain, Portugal, Hungary, Switzerland, Denmark, and Iceland made similar efforts after a few years. The method was based on encouraging all physicians to report the cancer patients they treated in the whole country. The report of these studies have indicated that only more than half of the physicians had filled in and sent back the survey forms and the failure of the studies has been recognized. In order to eliminate this handicap in the USA, Wood said in 1930 that cancer should be considered a notifiable disease. However, the first pilot study launched in Massachusetts in 1927 ended in failure after the collection of only the one third of the cases. Similar efforts were made for a while.

Being the oldest of all contemporary cancer registry centers, the Hamburg center was founded in 1926, based on the view that cancer control involves not only clinical and medical dimensions but also public health and economic dimensions. It gained its official status in 1929 and became a population based cancer registry center with full function in 1937. The nurses were visiting hospitals and physicians at regular intervals and collecting data on the new cancer-diagnosed cases. In the United Kingdom, the efforts that were launched in 1929 and that could be considered to be the kernel of a cancer registry center resulted in the opening of a national cancer registry center that covered the entire country in 1962. The National Cancer Registry Center in the United

Kingdom and Scotland is the population-based center that covers the widest population in the world.

The first population based cancer registry centers based on epidemiological and ecological aspects were opened in Connecticut, USA in 1935. Then other centers were opened primarily in developed countries.

The conference convened in Copenhagen in 1946 provided the greatest impetus toward the establishment of cancer registry centers worldwide. Twelve experts specialized in the field of cancer control recommended the proliferation of cancer control centers throughout the world to the Interim Commission of the World Health Organization. We can summarize the recommendations of this Committee as follows:

- a. Collecting data about the cancer patients from as many countries as possible will be beneficial
- b. These data should be collected within the scope of an acceptable plan in order to ensure “comparability”,
- c. Each nation should have a “central” cancer registry center to register and collect these data
- d. An international organization should be set up to gather and compare all data and statistics from each nation.

Four years later, WHO established a sub-committee working on this subject. The **International Union Against Cancer** organized an international symposium on the “Geographical Pathology and Demography of Cancer” in 1950. The importance of the detection of each new cancer case in a defined area was reemphasized in this symposium. **International Agency for Research on Cancer (IARC)** was established as the affiliated organization of WHO in 1965. This organization works especially on the carcinogenic effects of the environmental factors that healthy people are exposed to at their homes and offices and it prepares a monograph serial in this field (7).

As IARC deals with the various fields of cancer the need for a new organization that gathers cancer registries at an international level arose. To that end, **International Association of Cancer Registries (IACR)** was formed in 1966. IACR is a membership organization for cancer registry centers that collects and analyzes data on the cancer incidence in a given population, and that is interested in the outcomes of the cancer treatment. “**Cancer Incidence in Five Continents**” issued periodically by this union and that contains data of the cancer registry centers that collect sufficiently reliable and valid data, is the major reference in this field. The first volume of these serial books covers the data of the years between 1956 and 1964. The last volume (Volume VIII) was published in 2002 and it contains entries of the centers between 1993 and 1997.

Another cancer registry organization is the “Surveillance, Epidemiology, End Results” (SEER) which was established in the United States of America and that covers nine regions. SEER produces cancer data on the United States of America.

As of 1989, there are about two hundred population based cancer registry centers worldwide. In addition, 34 centers collect information on special age cohorts and the primary tumor site of cancer. According to the latest data, cancer registry centers covers about 7.6% of the world population. (8, 9). The prevalence of cancer registry centers throughout the world varies according to the regions and development levels of the countries (Table 1). Besides, hospital based cancer registry is conducted through units established in the hospitals and medical centers in various corners of the world.

In addition to IACR and SEER which were mentioned above in details, there are also international organizations such as European Network of Cancer Registries (ENCR), North American Association of Central Cancer Registries (NAACCR) and Middle East Cancer Consortium Cancer Registry Project (MECC CRP) which establish the standards of this scientific discipline and which undertake guidance in cancer registry.

Table 1- Ratio of coverage of the world population by the cancer registry centers

| Region | Estimated Coverage Ratio (%) |
|-------------------------|-------------------------------------|
| Australia / New Zealand | 73.9 |
| Western Europe | 23.3 |
| North America | 21.6 |
| Eastern Europe | 16.4 |
| South America | 8.5 |
| Asia | 2.7 |
| Africa | 0.6 |

Source: Crowley MJ. Cancer: The Irish Experience, The Epidemiology of Cancer in Southern Ireland, Statistical Laboratory, University College, Cork, 1995

Today, in addition to more than 350 population-based cancer registry centers, the majority of which is in developed countries, there are also centers that collect data on certain age cohorts (e.g. childhood ages) or on particular types of cancer (e.g. colon cancers) and also there are many hospital based cancer registry centers. While only 32 cancer registry centers had published reports in the first volume of Cancer Incidence in Five Continents in 1966, 40 years later IACR has gained 449 members, covering the 21% of the world population. (*Parkin DM, 2006*).

IV- Areas of Usage

Cancer control is the combination of efforts to which several types of persons and organizations contribute with different studies. Clinicians diagnose and treat the cancer patient; director of the cancer registry center evaluates the development of cancer in a population, epidemiologist searches for the reasons, decision makers and public health staff implement the protective measures and make the necessary decisions and laboratory staff try to find how a normal cell turns into a malign one.

While on one hand cancer registry is the basic part of a rationalist cancer control program, on the other hand cancer control studies are the fundamental motive for maintaining cancer registry activities. The collected data are used in a wide range of areas from epidemiological studies to the planning of health services for primary and secondary prevention and patient care for the benefit of both the society and the individuals.

The main target of a cancer registry center is to collect and classify information about all cancer cases in order to produce statistics on the cancer prevalence in a given population and to form a framework to evaluate and control the effects of cancer on the society. Although many cancer registry centers are not liable to perform more than the basic use of the collected data, they have a tendency to make progress and have the potential to support very important research projects by means of the information they collect.

After emphasizing the fundamental target of the cancer registry systems, we can list the areas of usage of cancer registry in accordance with the motto “the only way to show the necessity of cancer registry is to use its data.”

A. Epidemiological Researches

Cancer epidemiologists use the information on the distribution of cancer in the population in order to study on the determinants of this disease. Thus cancer registry centers provide the epidemiologists with vital epidemiological information about the distribution of cancer. Apart from displaying the incidences, cancer registry systems also assist in ensuring minimum error during the selection of samples in descriptive and analytical studies.

There are certain rates that should be known in order to identify the cancer distribution in the population. The principal rates are the *incidence rate*, *prevalence* and *mortality rates*.

Incidence means the *new* cases that occur in a given population (e.g. in the population of a province) in a given period (e.g. a year). Division of this figure by the population under risk gives the *incidence rate*.

Prevalence is the term that defines all cancer cases whether they are old or new and no matter when the diagnosis is made. Cancer prevalence is estimated by using cancer incidence rates and survival rates.

Cancer mortality is the number of deaths the major cause of which is cancer, in a given period (e.g. in a year); mortality rate means the division of this figure by the population under risk. Generally, the registries of deaths are kept better than those of diseases, and therefore mortality rates can be reached even in many countries where registry on cancer is not kept.

1. Descriptive Studies (dimensions of the problem): The statistics to be produced by the cancer registry center are identified according to local requirements and interests and by considering international comparability. As it was mentioned before, the most essential and the best known function of the cancer registry center is to estimate the current incidence rates of cancer specific to primary tumor sites (topography), age cohorts, gender, geographical regions, occupation, etc. Denominator (distribution of the population by gender, age cohorts and occupation etc) should be known accurately in order to estimate these rates. For example, using the census results of 5 years ago in a region that faces substantial migration in a short period of time would be misleading.

In addition to the incidence rates, prevalence statistics also complement the basic information on the cancer prevalence in a society. These statistics may be derived mostly from incidence and survival rates. However, if the cancer registry centers established a long time ago collect the death and migration data of all cancer cases in their respective regions, the basic data of the registry centers can be used in calculations. The records of the Cancer Registry Center in Denmark are a good example for this situation.

Comparing the incidence rate of cancer cases in various population groups provides etiological hints. Observing the differences in incidence and mortality rates contribute significantly to the discovery of the environmental origin of many cancer types. Occupational exposure can be shown in this way. These methods assist in taking protective measures for the society.

Regional or urban / rural differences, incidences in ethnical or religious groups can be compared with each other according to the extent of the area covered by the cancer registry center and to the characteristics of the population, and the observed differences can provide significant etiological evidences. For example the cancer incidences of the populations that immigrated to Israel from different parts of the world are different from each other. Since many cancer types are diagnosed microscopically, the histological types can also be reviewed and connections can be made between the etiology and histological types.

Another area of study of the cancer registry centers is to examine and interpret time curves, especially through forming age cohorts. Sometimes cancer registry centers may detect a cancer epidemic. For instance the epidemic of the uterus corpus cancer caused by the extensive use of estrogen in the postmenopausal period have been detected in California in this way.

Cancer registry centers record also the multiple primary tumors in a person and this information creates a database to understand the relation between various tumors in persons.

International comparison of the changes in the cancer incidences is another contribution of the cancer registry centers. In order to mention the existence of a meaningful difference in the international studies, diversities in the nomenclature and interpretations should be eliminated. Systematic comparisons can be found in the monograms in “**Cancer Incidence in Five Continents**” (*Parkin DM and friends, 1992; Parkin DM and friends., 2002*) issued periodically by IARC.

2. Analytical Studies (Causality): Concerning the nature of statistics, one can hardly mention causality in descriptive studies; observations obtained through descriptive studies should be analyzed with more detailed researches. The cancer registry centers, which constitute a rich data base to conduct such analytic researches, are the organizations where necessary information of the selected cases are available. Today, it is found out relatively easily that some important factors such as cigarette addiction, excessive use of alcohol, radiation and certain industrial agents cause cancer (in other words they increase cancer incidence in the population). However, studies which include greater population groups concerning connections that require more detailed researches and that are difficult to prove, such as the effects of life styles and diet on the cancer risk are continuing.

Cross-Sectional Studies; compare cancer incidence and mortality rates with the levels of exposure to the potential risk factors in various population groups. As an example, we can mention the studies that show the relation between the consumption of fat and breast and colon cancers (*Armstrong B, 1975*) and the relation between aflatoxin exposure and hepatocellular carcinoma (*Linsell CA, 1979*). This kind of research is very useful in creating hypotheses. But the presence of confusing factors should not be neglected while making reference to these relationships. Therefore it is necessary to make use of a variety of research methods together.

In *case-control type* studies the past exposures among the cancer patients (i.e. in the “case” cohort) are checked. Theoretically, population based cancer registry centers are ideal case sources for case-control studies. The cases represent the whole community and therefore a bias caused by the characteristic of the data base is out of question when the controls are selected with the right method. Case-control studies are the robust and economic way of testing the hypotheses, but a direct cause and effect relation can not be established by this kind of study except that certain projections can be made on which factor increases the risk. Whether there is a correlation between the doses of the risky factor and its effect (the increase in the cancer incidence) can not be understood in the case-control study.

Cohort type studies should be made in order to establish a cause and effect relation between various factors and cancer incidences. In a cohort study many people who are not cancer patients are asked questions about exposure to potential risk factors and these people are monitored in order to determine if they are exposed to suspected factors and get cancer. Thus, it can be observed that the lung cancer development rate is higher in the smoker group than that of in the non-smoker group. Cohort studies have significant advantages; for example the outcomes and cause and effect relations reflect substantially the reality since the presence or absence of the disease in the past is definite.

After primary data are collected, researchers wait for sufficient number of cases to be collected from the persons included in the study. As can be guessed, this waiting period is quite long. For that reason using the routine registry systems is much more advantageous than creating “*ad hoc systems*” (*systems that are established to execute and finalize a special task and terminated upon the completion of the said mission*) to monitor the patient. Although death certificates can be used for this purpose, cancer incidence rates provide extremely satisfactory results for cohort studies. There is a direct proportion between the length of the term of office of the cancer registry center (meaning the oldness) and the extensiveness of its coverage area, and the availability of its data in the cohort studies.

The importance of the cancer registry centers in intervention researches should also be mentioned. When the potential risk factor is eliminated a decline in the related cancer incidence is expected. This decline can be noticed in the incidence curves formed by the cancer registry centers. However, usually long years should pass in order for this effect to be observed and detected.

B. In Cancer Control

Cancer control is a term that includes all components of prevention, early diagnosis, treatment, rehabilitation and palliation. World Health Organization (WHO) states that cancer control activities should be conducted within the framework of a national cancer control plan and that the population based cancer registry centers are the core of cancer control strategy (*WHO, 2002*).

1. Planning the health services (priorities, targets, projections and estimations): Cancer registry systems ensure our access to the information on the cancer cases in our population. The data routinely collected by the Cancer Registry Centers allows the identification of the dimensions of the problem, the needed quantity of hospital bed, personnel and device-tool. This information serves as a guide in planning and establishing the diagnosis, treatment and care units for different types of cancer. We can also use this information for the establishment of needed number of bed, personnel and device and tools. Geographical differences or the changes that occur in due course can be taken into consideration by following the time curves. The identifications about the tendencies allow making proactive projections and using them in planning. By following the *patterns*, we can say where and when opening new diagnosis and treatment centers will be cost-efficient.

2. Prevention: Randomly controlled studies are rarely organized for the evaluation of preventive intervention studies. However, we can evaluate the effects of the intervention made by comparing the expected and observed incidence rates after waiting for a sufficient time for the beginning of the effects and by employing the incidence rates provided by the population based cancer registry centers.

3. Clinical Care: Cancer registry centers can indirectly contribute to the patient care through assisting in monitoring the patients by forwarding to the clinicians the list of the patients that should be monitored. Moreover, cancer registry centers can support the patient care directly by contributing to the patient care programs organized to implement the diagnosis and treatment methods defined for a certain type of cancer.

4. Screenings: Screening of the asymptomatic persons has an ever increasing importance for the early detection of cancer. Cancer registry plays a significant role in evaluating the screening programs. For example

the efficiency of a cervical cancer screening program is measured through following the incidence rates produced by the cancer registry center. An effective screening program will provide a decline in the invasive cervical cancer incidence. In breast cancer screenings, since the number of cases diagnosed early will increase, the incidence rate will also increase but the mortality rate will decrease. In other words, the main outcome of the breast cancer screenings is the breast cancer mortality. Cancer registry centers can evaluate the success of the screening program by defining the mortality rates, stage distribution and the number and percentage of interval cancers (cancers detected between two screenings) among the women included and not included in the screening.

Many mammography screening programs are being conducted for breast cancer control in Europe where breast cancer is the most common cancer in women. The importance of the cancer registry in cancer control is mentioned in the European Parliament publication dealing with these programs and it is emphasized that all European countries have their own cancer registry systems covering the entire or a part of the country (*European Parliament, 1994*).

5. Conclusion: survival and quality of life: Most cancer registry centers gather data on cancer-related deaths. Population based survival rates are estimated by using this data. Population based survival rates are very important for the patient care and health care planning. The only way to show that one treatment method is better than the other is to perform clinical studies. Generalizing the survival rates of the selected patients in a small-scale study causes bias. However, the cancer registry center can evaluate the survival periods of all cancer patients by comparing the death certificates with his records at hand and by covering the non-treated cases in its region. Since survival rates will be affected by the presence of screening activities conducted for the early detection of the disease in the population, it is used as not only the output of the treatment services but as a medium to evaluate totally the functioning of the health system and the qualities of the health services.

Certain cancer registry centers can estimate the patient survival rates by collaborating with a certain service or clinician and compare these rates with those in the registry area. Cancer registry centers collecting detailed information on the treatment can evaluate the current treatment or assess the role of radiotherapy and chemotherapy treatment methods in causing secondary neoplasm. Collection of data about the prevalence of the tumor through an appropriate and standardized method (TNM, FIGO, SEER, etc) allows the production of statistics about the survival rates in cancers with different sizes and prevalence.

Survival that we can define as the average of the years pass after the diagnosis is definitely a rough indication of the real result, but it is relatively easy to measure. The value of the years in the accompaniment of pain and handicaps is questionable. Therefore, the survival measures are refined either in medical-surgical categories such as survival without disease and survival without metastasis or by evaluating the quality of life in the period between treatment and death. Measurement of the quality of life concerning health involves a complicated information collection process and is not a part of routine cancer registry.

C. Other Areas of Usage:

In addition to its mission to register and use this data, cancer registry centers are also a source of data for the hospital departments and research institutes that need the list of cancer patients in order to produce statistics.

Cancer registry center staff is well-informed about the disease registry, epidemiology and public health issues. For this reason, the staff in the cancer registry center can serve in training activities not only in cancer epidemiology but also in epidemiological methods. They can assume the production of training devices and tools for pre and post graduate training and public education.

Cancer registry center staff may provide the experts in this field and the public with consultancy in disease registry, causes of cancer, cancer control and planning of the cancer care.

D. Necessity of Cancer Registry

The necessity of cancer registry may be questioned from time to time. It is argued that many functions of cancer registry centers can be performed by the *health statistics offices* by using death certifications, hospital statistics or the combination of data collected from both sources. In Turkey where it is known that death certificates and hospital registries do not reflect the reality, it is not possible to receive accurate results based on this data. However, it is appropriate to mention the reasons that prove the necessity of cancer registry centers compile cancer data separately in developed countries where these registries are kept attentively, accurately and fully. These reasons can be summarized as follows:

1. Cancer is recorded in death certificates only when cause of death is cancer and survival times of the cancers that have different histologies of different topographies vary in a wide range of periods. For these reasons

mortality rates do not show the real figures about the incidence of the disease. For example this is valid 100% in lip cancers and less than 10% in lung cancers. The cancer incidences derived from the data of the cancer registry centers includes the non-fatal cancers and therefore it indicates the real cancer risks much better.

2. The data of the cancer registry centers are detailed to display the differences in the trends of different cancer types. For example together with the decrease in lung cancer incidences in developed countries, a decrease in small cell carcinoma among the lung cancers, the relation of which with smoking is proved,. On the other hand, an increase is observed in adenocarcinoma which is thought to have the least relation with smoking, and this corresponds to the decline of smoking prevalence in developed countries. Even if we estimate the lung cancer incidence from the death registries with a 10% error, the tendencies in the occurrence of histological types can only be observed through processing the data of the Cancer Registry Centers.

3. In the cases where cancer is recorded as the cause of death in the death certificates, mistaken notifications can be made about the primary tumor site. In their researches, Percy C. and his friends noted that tumor sites such as lung and pancreas are recorded correctly in the death registries but he also stated that larynx, bone and colon are over-recorded, and uterus cervix, endometrium and rectum are under-recorded (*Percy C and his friends, 1981*)

4. Data on multiple primers can also be missed in death certificates and hospital data. For example, if a person receiving testicular cancer treatment dies of "iatrogenic leukemia", one of these two cancers is registered as the cause of death and the other is not indicated in the statistics.

5. Hospital statistics may provide more detailed information but in general there are also errors in these registries. For example, representations may be included in the registry and since patient names are not used, the patients presenting to different institutions cannot be distinguished. And this causes the inclusion of the duplications in the incidence which may cause, in return, incorrect outcomes.

To sum up, while the use of death certificates may cause the underestimation of the cancer incidence rates than it really is and the use of hospital statistics for this purpose may cause the overestimation of these incidents than it actually is. The possibility that the hospital registries may be worse in quality than those of a cancer registry center should not be avoided. Data such as death certificates and hospital statistics are not sufficient alone for the establishment of the cancer incidences and for the monitor of the patterns. Information about cancer cases should be compiled by staff that have special training in this subject

by scanning different sources, and the gathered data should be interpreted by experts who are knowledgeable and experienced in this very subject.

V. Confidentiality:

Cancer registry centers always apply very strict confidentiality rules and regulations about the protection of the secrecy of medical and personal information and the release of this information to the third parties (persons, legal entities). IACR, taking the fundamental principles in this issue as a basis, prepared a “Guideline for confidentiality in cancer registration” for cancer registry centers. (*IACR/IARC, 2005*).

VI. Cancer Registry Systems

A. Data Collection Methods

1. Active: Active data collection is the establishment of the cancer cases by the own staff of the cancer registry center (cancer registrars) by getting in touch with the health institutions by using every possible way and compiling these data on the cases in accordance with the international cancer registry standards. The point in question here is to obtain the data from its source. The basic person of a cancer registry system using active data collection is the “**cancer registrar**”. Generally persons from various professions of medicine and health sciences receive special training and they are given a certificate and the title of “cancer registrar.” Collection of data by this staff with special training and certificate is vital in cancer registry. Since data collected randomly and without certain standards cannot be evaluated in itself, they cannot be compared with the data of other centers and countries either. Moreover, in order for a cancer registrar to be efficient enough, he should be dealing with this work full day, he should be serving in an organization that evaluates his work and should have the opportunity to have in-service training.

2. Passive: This system is based on automatic sending of the data on cancer cases by the staff working in the related institution (for example in a hospital) to the centers as a method. It should be considered that in passive data collection, in addition to quantity problem (notification of the small percentage of the observed cancer cases), there will also be a quality problem (since the standards will not be followed). In Israel where passive method is implemented successfully, the notification is not made through a form that is composed of several headlines but the patient’s all findings and documents on cancer are sent to the cancer registry center.

3. Linkage: It is the inclusion of the data which is collected in a certain way and entered into the computer system, i.e. in an electronic form, into the data of the cancer registry center by using the computer network. The cancer registry centers in most developed countries use mainly this system. We should emphasize that also in this method the data that should be conveyed is not the particular headlines such as the name and surname of the patient, cancer etc but all findings and documents about the cancer case.

B. Cancer Registry Centers

1. Population Based Cancer Registry Centers: When the term “Cancer Registry Center” is used generally the population based cancer registry centers are understood. In this text, unless otherwise is stated, we mean “population based cancer registry center” when we say “cancer registry center.” Population based cancer registry center is an organization that records all malign tumors that are newly diagnosed among people in a well defined population (mostly in a geographical area) by observing the concepts of epidemiology and public health. In this sense, population based cancer registry can be defined as the continuous and systematic collection of data on the incidence and characteristics of all malign neoplasm observed in a certain population, in a community in order to evaluate the effects of cancer in the society and to help cancer control.

A population based cancer registry center,

a. Collects data on all cancer cases that occur in a well defined population during a certain period of time by making use of all data sources (hospital records, oncology centers, registries of pathology and radio diagnostic centers, death certificates, health insurance, etc), complying with the international standards.

b. Its basic aim is to establish the cancer incidence rates in the subject-matter population, to estimate the distribution of these incidences by age groups, gender, etc, to scrutinize the changes in due course and to form a new database for the researchers.

c. It needs accurate and detailed demographical information about its responsibility area in order to estimate these incidence rates.

2. Hospital Based Cancer Registry Center: Hospital based cancer registry centers registers all cancer cases presenting to the hospital in which it is located without regarding any population background. The main purpose here is to have access to the data on the clinical care of the patients and the hospital management. Hospital based cancer registry

center serves the needs of the hospital management, hospital's cancer programs and above all the "patient" individually.

The information collected about the cases are more detailed than those of collected for the population based centers; a good-working hospital registry center can collect very detailed information about the treatments and monitoring materials.

A hospital cancer registry center collects information only about the patients who present to the center and this information reflects the characteristics of the hospital. Therefore, the collected information can be generalized only under very limited occasions and certain conditions. This situation is a significant constraint in the hospital cancer registry centers.

However, hospital based cancer registry centers constitute generally the core of population based cancer registry centers in its region and they forward the necessary amount of the collected data to the population based center. Since founding a population based cancer registry center is an economic problem especially in developing countries, establishing a hospital based cancer registry center may be the first step of such a comprehensive work.

3. Pathology Based Cancer Registry Center: There is no population background here either. The diagnoses given in the pathology laboratory of any hospital or a group of hospital constitute the data base. This type of centers collects all cancer cases diagnosed at tissue or cell level, i.e. with pathological or cytological methods, but do not collect cases that do not have histological diagnosis (that are diagnosed with clinical observation, ultrasound, computerized tomography). Pathology based centers compile data on both new cases and metastases. The purpose of this kind of registry centers is to conduct scientific clinical studies especially about the morphology of cancer.

In addition to these three different methods there are also cancer registry centers that collect cancer case data on a certain age range (for example childhood period) and on a single type of cancer (for example ovary cancer) or a group of cancer cases (for example female reproductive organs).

VII. Comparability and Quality Assurance in Cancer Registry

A. Comparability:

In order for the data of a population based cancer registry center to be accepted by the international scientific circles it has to fulfill certain international comparability criteria. In other words, the statistics produced by a cancer registry center should be comparable for different

populations and / or different periods. The basic prerequisite for comparability is the adoption of global standards and rules. Rules and the documentation of change of these rules, a good coding and the use of a classification system are the factors that effect comparability. Quality assurance of the cancer registries starts with the proper foundation of the organization, setting up the data collection rules in the center appropriately and finally employment of competent staff in the task, and strengthens with the activation of in-service training and data control mechanisms.

Factors Affecting Comparability

1. Rules and Certification: The headlines of the collected data and related terms should be defined clearly, a “rules and definitions” guide should be prepared, and the changes made in the rules or definitions in the course of time should be documented. If certain cases require a subjective decision, this decision should be reviewed by an experienced staff and it should be certified in written by stating the reasons and for using as a guide in a similar situation that may arise in future.

The rules must be clearly established for basic data headlines such as the type of the case to be included in the data base (multiple primary or relapse) or the date of diagnosis.

2. Classification and Coding Systems: In a good coding system only one appropriate code exists for each appropriate term. The changes made in the coding system should include the information about the effectiveness date of the changes. Therefore while on one hand a systematic should be developed for the diagnosis given, on the other hand the standards for the main data headlines should be presented. The most frequently used list for diagnosis systematic is the “*International Classification of Diseases for Oncology*” (**ICD-O**) developed by WHO for this purpose. **ICD-O-3**, the third version of this list is extensively used by the cancer registrars throughout the world.

3. Standards: Cancer registry center should have certain standards. Acceptable error rates for main data headlines should be established and when the error rate exceeds this level, necessary action should be taken to lower this rate.

B. Accuracy:

Apart from the comparability of the cancer registry center data, it should also be “**accurate**” (**definite, complete**). The scientific accuracy of data set is affected by two components: 1) completeness of the data and 2) **validity** of the registry. The process of control of these two components is called quality assurance of the data.

1. COMPLETENESS: The completeness of the registry can be defined as access to all new cases occurred in the target population and the entry of all these cases into the database of the registry center. The lowness of the completeness degree will cause underestimation of all incidence rates and may cause lower or higher results for certain types of cancers.

These are the methods to measure completeness:

a. DATA SOURCES

i. number of notifications / sources per case

- The highness of the average number of notification per case means the highness of the completeness degree of the registry center.
- Average number of source per case
- Average number of notification per case

ii method of death certificate:

- Death certificates are used in cancer registry for three purposes:
- Detection of new cases to complete the data base. The cases with OSS (Death Certification Notification-DCN) and the cases with OSY (Death Certificate Only-DCO)
- For Quality Control (both for completeness and for validity)
- Survival studies

There are methods of making completeness estimation with death methods. Here is a simple example:

$$1 / (1-OSS) + (OSS/M:I)$$

Basically DCN cases are desired to be lower than 10% of all data set.

iii. Use of Histological Verification Rate of the Diagnose in the Completeness Control (HD):

The histological or microscopic diagnosis rate of the registered cases is a method used extensively in measuring the validity of the data of a registry center. However, we can make use of this criterion when checking the completeness. Very high HD percentages show that clinically diagnosed cancers are undetected, meaning that the completeness percentage of the registries is low.

b. INDEPENDENT CASE STUDY

i independent case sets:

Since the cancer registry centers try to reach all potential data sources, it is very difficult for them to find an independent serial of data with which they can compare their data.

- Limited serials of data: Data serials and autopsy serials formed for special studies (clinical researches)

- Comprehensive Case Registries: The patient Management System in Denmark and the records of the general practitioners in the Netherlands can be given as an example. In the Cancer Registry Center in Barshi / India the completeness is checked with the research on households.

ii. re-scanning the cases:

All cases in a certain period of time are re-scanned by searching the potential data sources. The missed cases are detected and estimations are made on the number of missed cases.

iii. Capture / recapture method:

It can be implemented without making additional effort in the centers that have multi source case detection system. For example hospitals / pathology laboratories.

iv. mortality: incidence rate (M:I):

M:I percentage, i.e. the proportion of the number of deaths referred to a certain type of cancer in a certain period of time to the number of patients who got this disease is expected to be lower than 1.

c. CHRONOLOGICAL DATA METHOD:

The number of cases is compared with the “expected” number of cases obtained from similar populations.

i. changes in incidence rates in due course:

The time curves obtained may be compared with those of similar populations.

ii. comparison of the incidences in different populations:

The results of the center may be compared with those of other populations considered to have similar characteristics.

ii. age-specific incidence curves:

The incidence rates for many epithelial cancers increases in parallel with age. Since most of the cancers have epithelial origins, it can be said that this peculiarity is valid for all cancer sites over the age of at least 15. Generally, it is normal to observe a decline in the increase of the incidence rates after the age of 70.

This rule has certain exceptions:

- The incidence rate of nasopharynx cancers peaks in the early ages (15-24 years old) in the South African populations.

- If the cigarette smoking history is a new case in the population, a low lung cancer incidence rate is observed in advanced ages.
- A decline is observed in the age ranges after the peak in the bone cancer incidence in young ages (15-19 years old). After the age of 30, an increase is observed again.
- Strong cohort-specific patterns are observed in the malign melanoma incidence. Today higher incidence rates in earlier ages are observed.
- Cervical cancer incidence rate peaks at the ages of 45-50.

iv. Childhood cancers:

Generally, the incidence rates in the childhood age range show a tendency to decline in the first three to five years old age group. Different models for certain cancers are defined in particular populations. The sequence of the most frequent childhood cancers does not change in general from population to population. Leukemia is the most frequent cancer in children. It peaks at the age of 2-3. Then while the brain tumors rank the second in more advanced countries, the lymphomas come the second in less developed countries, depending on the prevalence of related infectious factors.

2. VALIDITY:

As a basic component in evaluating the quality of the cancer registry center data, validity is the concept of how much the data and the information abstracted from this data are close scientifically to the reality and accuracy.

These are the methods to evaluate validity:

a. Diagnostic criteria method

It establishes the percentage of the cases that include all criteria of diagnostic completeness.

-*Histological Verification:* The highness of the percentage of cases the histological verification of which is made is a positive indication for validity.

-*Death Certificate Only (OSY):* The diagnosis of a case is established to be “death certificate only” means that we do not have any idea about the diagnosis processes of this case. The highness of OSY rate of a case is a negative indication in terms of validity.

b. Incomplete Information:

The rate of cases about which there is incomplete information in terms of significant data headlines is an important indication.

- *Primary site is not known*, or a badly-defined site of tumor

- *The age is not known*

- *Other incomplete information:* gender, diagnosis date, histological type, place of residence, date of birth

c. Re-abstracting and Re-coding:

-*Re-abstractation of the routine cases:* As the part of routine study, the cases selected by sampling are re-abstracted and re-coded completely

independent from the previous reporting and by using the information taken from the source.

- Re-abstraction of certain cases

Certain cases may be re-abstracted by more than one component for testing, practicing or studying purposes.

The discrepancies between the two abstracts of the same case are recorded as major / minor discrepancy (major / minor discrepancies are defined for each headline) and these rates are reported.

d. Internal Consistency Method:

This method is based on checking the consistency between the headlines of data collected about the case.

- Are the compulsory data complete?
- Are the age/diagnosis date /date of birth consistent?
- Are the diagnosis date / last monitoring date / date of death consistent?
- Are the gender and topography consistent with each other?
- Are topography / histology / behavior consistent?
- Are / topography / histology consistent?
-
-
- There are computer programs that make consistency checks. These are:
- CANREG-4
- IARC-CHECK (Control Programs)

VIII. Cancer Registry in Developing Countries

A. Characteristics

In developing countries, since cancer is not regarded as a primary health issue yet, and since cancer competes with infant mortality and infectious diseases in the distribution of limited financial sources, cancer registry can be considered to be a luxurious concept at first glance. In fact, this is a wrong belief, because:

1. Cancer is an important health issue for the developing countries as well and this problem has the tendency to grow in future.
2. The presence of an adequate information system is the fundamental need for any kind of cancer control strategy.

For the persons who have completed the first five years of their lives, cancer ranks among the first three causes of deaths both in developed and in developing countries. Although reliable death registries and medical records of cancer or other diseases can be derived respectively from only the 4%-3% of the population in the underdeveloped countries, estimates of cancer incidence and mortality rate for different regions are made. It is estimated that cancer incidence rate for 2005 will be 435 in hundred thousand for developed countries and 120 for less developed countries. Given that 81% of the 6.5 billions of the world population are living in

developing countries, and in spite of 5.26 new cancer cases to be observed in developed countries every year, it is calculated that this number will reach 6.3 million (*Ferlay J and his friends Globocan 2002*). For 2005, 55% of 11.6 millions of new cancer cases in the world is estimated to be seen in the developing countries. Worse than that, 4.36 millions, i.e. 61% out of 6.3 millions of cancer deaths estimated for 2005 will be seen in underdeveloped countries. As these countries have a young population, although the coarse incidence rate seem rather low, age-specific risks are in fact not lower than those of the more developed countries. However, the differences in the cancer types are evident. For example, although cervical cancer and primary liver cancer is less prevalent in European and South American countries, it is prevalent in developing countries.

It is obvious that cancer will be one of the most important problems of the health system of the developing countries in the decades to come. Because;

1. The population is not only increasing but also getting older depending on the factors such as immediate control of the infectious diseases and infant mortalities.

2. “Western life style” becomes frequent in these countries, a rapid urbanization period prevails which results in an increase in risk factors.

3. In addition to real increases, factors such as the increase in the diagnosis and treatment opportunities in these countries and decrease in deaths from other diseases bring about the “relative increase” in cancer cases.

In spite of all these factors, only a few developing countries have a comprehensive cancer registry system. Thus these countries achieve both the planning and evaluation of the cancer control activities in an economical way and have access to basic data for researches in the field of etiology and protection from cancer.

B. Challenges

Both the health services and registry systems in developing countries encounter certain challenges. These challenges also affect the cancer control and cancer registry. In line with the purposes of this text, the problems encountered especially in the developing countries are as follows:

1. Deficiency of basic health services

Depending on the deficiencies of the health services in the developing countries, cancer diagnosis and treatment opportunities are also limited. Although most of the population is living in rural areas, health institutions and health care personnel are operating mainly in big

cities. Therefore, although these institutions collect cancer data precisely, it is obvious that this will not be representative of the entire population. The people tend to present to traditional healers for medical problems, which means the non-inclusion of the cancer data into the registry center.

Medical staff in very crowded health institutions may be too busy to keep precise and detailed records. The insufficiency of diagnosis and treatment capabilities also hampers the access to true cancer data. First of all, the information on diagnosis is inadequate and mostly based on clinical observation. Secondly, the patients at the further stages of the disease or who are not treated may not present to hospitals. Since the diagnosis of superficial cancers such as the skin cancer may be made through a biopsy to be taken, it has a higher detection rate compared to the liver or pancreas cancers that require the use of expensive techniques for its diagnosis. Examination after death (autopsy) is rarely performed, in which case it is not reported in the registries, even if cancer is detected.

2. Lack of Demographical Data

Most of the developing countries do not have reliable demographical information on the entire population. Moreover, classification by gender, age and ethnic groups may not be reliable. In addition, there is a steady flow and migration of people for various reasons in developing countries and most of the time these movements cannot be recorded.

The persons must be distinguished in order to prevent duplications. Distinguishing people from each other apart from the flows of population is also a difficult task. Every person has an identity number in more developed countries. However, since the majority of the less developed countries do not have such a system, criteria such as name, surname and father's name are used to distinguish people from each other, which may not provide a full distinction.

3. Lack of Trained Staff

Data collection, accumulation, analysis, interpretation and ability to use this data require the collaborative work of highly qualified experts trained in different disciplines. Perhaps the most important problem in cancer registry in developing countries is the lack of sufficient number of staff that has related training. This insufficiency may extend from the cancer registrar as the first link of the chain to the oncologists and pathologists to make diagnosis on the codes, statistics experts to make the analyses and epidemiologists to interpret the data. The data obtained after overcoming these obstacles usually cannot reach the health planners or is avoided.

4. Lack of Patient Monitoring:

Monitoring data allows the cancer registrars to review the accuracy of the initial registers. In addition, this data is also necessary to measure the effectiveness of the treatment and calculate the survival rates. Reaching

the monitoring data in underdeveloped countries is almost impossible. Limitations in the use of telephone and posting services and continuous flow of population make it difficult for the patients to remember their appointments. Even if it is achieved, the patients may not answer the calls. It may also be impossible to have access again to the registries of the patients that have responded the calls.

5. *Lack of Devices and Tools, Financial Problems:*

Even if cancer registry is launched in developing countries, since it is not a service directly related with treatment it may generally be avoided and it may not be allocated funds. This means inadequate fulfillment of the indispensable needs of a cancer registry center such as primarily the working place, stationery, paper, photocopy utilities, communication and transportation expenditures and computer.

6. *Failure to Achieve Institutionalization*

A population-based cancer registry center has to collect data from all private and public health institutions that make cancer diagnosis and treatment in its region. In addition, it needs death certificates and demographical data coming from the institutions other than health institutions. Legal arrangements must be made for the smooth performance of the activities. Most developing countries do not have such regulations.

C. Future

The required items, in order to be able to raise prospective hopes for improvements in cancer registry in developing countries, can be listed as follows:

1. Forming a national cancer control and cancer registry policy
2. Provision of reliable, continuous and steady demographical data
3. Reactivating the previously established cancer registry centers and establishing new ones.
4. Ensuring the training and the continuity of the trained personnel needed for cancer registry centers.
5. Providing the structure, i.e. institutionalization, for permanent positions for the cancer registrars, regulations that include arrangements on data collection and the provision of necessary sources.

IX. Cancer Registry in Turkey

Cancer, which occupied the fourth rank among causes of death in Turkey during 1970's, has risen to the second rank after the cardiac diseases today. When deaths at all ages are considered together, it is observed that one death out of every ten is caused by cancer. The efforts

to prepare and implement effective cancer control programs in Turkey are increasing in recent years.

Through the Circular of the Ministry of Health numbered 5621 and dated 14.9.1982, cancer is included in the scope of notifiable diseases stated in Article 57 of the Public Health Law numbered 1593. In accordance with this Article, all public and private physicians who have given a cancer diagnosis are liable to report this to the nearest health institution.

Thus, Ministry of Health has started, as of 1983, to collect the cancer data throughout the country with passive method based on the reporting of the physicians and health institutions making cancer diagnosis. Although it was estimated that the total cancer incidence in Turkey was at least 150 in hundred thousand and therefore 90-100 thousand new cancer cases would be observed in a year, the number of cases collected through passive method throughout the country could not exceed twenty thousand in a year. This system was previously tested in developed countries but it failed. The point we reached is that: "thousands of collected forms became piles of data that are insufficient in terms of both quantity and quality, and accurate information on the cancer epidemiology in Turkey could not be obtained."

Scientific circles in the cancer registry discipline find the 10% coverage of the population sufficient, provided that the coverage rate of cancer registry activities in a society is the representative of the socio-demographical characteristics of that society. The specialized experts who came to Turkey as observers or advisors proposed the establishment of population based cancer registry centers collecting data through active methods in certain provinces rather than passive data collection (notification) throughout the country.

In this way, instead of a nationwide data collection without completeness and validity meaning without reliability, it was decided to establish a cancer registry system representing the entire population and collecting data actively in an area that has pre-defined geographical and demographical borders and the Department of Cancer Control launched the "Cancer Registry and Incidence" project in 1992.

Activities on establishing a cancer registry center based on a population in a region the borders of which were well defined started in İzmir in 1991; the efforts have begun to establish population based cancer registry centers using active data collection method in Diyarbakır, Ankara, Trabzon, Edirne in 1993, in Antalya and Adana in 1994, in Sivas, Erzurum and Bursa in 1995 (there are 15 million people living in these cities). As the part of the "İzmir Cancer Incidence and Data Collection Project" (İKİP), İzmir Cancer Registry Center which was activated in 1991 through a special protocol signed between the Ministry of Health of the Turkish Republic, Turkish-American Health Research

Center and the Aegean University, is Turkey's only population based cancer registry center the data of which are acknowledged by international scientific circles. More detailed information about the İzmir Cancer Registry Center will be given later (Section X). The incidences for 1994 calculated by means of the cases collected from the above-mentioned provinces are as follows: (in hundred thousand) 60 in Diyarbakır, 60 in Ankara, 59 in Trabzon, 84 in Edirne, 36 in Adana and 103 in Antalya. Since initially Ankara was the center of these studies and since it lacked necessary infrastructure for a cancer registry center, it cannot be said that these efforts were successful. The outcomes were not realistic and doubts about the data reliability and validity were raised. However, in subsequent years, İzmir Cancer Registry Center was accepted as a sample model and the establishment of other cancer registry centers according to this model was emphasized. The training of the staff working in these centers was intensified and especially the locally successful centers were supported. Providing impetus to all these efforts, the "Regulation on Cancer Registry Centers" was issued in the Official Journal numbered 24260 on December 14, 2000 and began to be implemented. Thus cancer registry has reached a good level today in Antalya, Adana, Trabzon, Samsun and Bursa provinces. It is envisaged that these centers will attain the level of reporting incidence rates with scientific accuracy within the next several years.

X. KIDEM: İzmir Cancer Registry Center

İzmir Cancer Registry Center, or with its official name "İzmir Cancer Monitoring and Control Center"(KIDEM) is the first population based cancer registry center the geographical boundaries of which are well-defined (İzmir province) and which aims at accessing the data of all cancer patients within these boundaries (www.ism.gov.tr/kidem). The objectives of KIDEM are, like all other cancer registry centers, to collect information about cancer cases occurred in Izmir province by using all kinds of data sources, to calculate incidence rates of different cancers in Izmir, to establish the distribution of these incidence rates by age groups, gender and regions, by evaluating incidence rates lower or higher than expected, to make estimations to reveal new researches about specific cancer causes for the region, to create a data-base for scientific researches and to assemble reference evidences for projects to control cancer.

Upon the signature of the protocol between the Ministry of Health of the Turkish Republic, Turkish-American Health Research Center and the Ege University, İzmir Cancer Incidence and Data Collection Project (IKIP) was launched in 1991. The target of this project which was initiated after establishing hospital based cancer registry units in big hospitals, training the nurses as cancer registrars to work in these units, is

to ensure the central registry of the current cancer cases in İzmir province and monitoring and evaluating them statistically. Its aims were as follows:

- *Ensure standard data collection in centers making cancer diagnosis in İzmir province and making data collection a routine procedure

- *Verification of the collected data and performing quality controls

- *Publication of the obtained data at regular intervals and making them available for national and international users

- *Conveying the experiences gained here to the other regions of Turkey and contributing to the launch and execution of similar cancer registry activities in those regions.

Ege University Cancer Control, Practice and Research Center (EUKAM) was established on December 30, 1991 for the execution of project studies. İzmir KİDEM that is subordinate to the Provincial Health Directorate was established on March 13, 1993 and the coordination of the project activities was transferred to this center. KİDEM, the organization and activities of which are mentioned below still continues its activities within the body of İzmir Provincial Health Directorate.

We can summarize the first period until 1995 as follows: There was no central office for administrative coordination and there was lack of standardization between the hospitals; collecting “very detailed data” about the cases was given priority and the coverage of all cases in that unit was disregarded; no other data source other than hospitals were used, therefore, the completeness of the data base was not achieved. Recognizing that this system is not suitable for a population based center, a restructuring process was launched in 1995-1997. A new central office equipped with scientific and administrative capabilities was established within the body of İzmir Provincial Health Directorate and the coordination of the project was transferred to this center. The center was provided necessary infrastructure and technical equipment such as computer and etc. In-service training programs were organized and with scientific assistance from domestic and foreign experts, the data collection form was renewed, mobile cancer registrars were trained to serve in the center for collecting data from the institutions other than those that have hospital based units and international comparability was focused on. Studies to reorganize all structures to ensure more effective data collection and reaching a completeness and quality level that will allow recognition by the international scientific circles were completed in 1998. Necessary arrangements were made to enable the mobile cancer registrars to collect data that have appropriate standards from public or private institutions which examine cancer patients. Finally, in 2000 the Regulation on Cancer Registry Centers, which gave fresh impetus to these studies was issued and was put into effect. Collecting data from all institutions that diagnose and / or treat cancer cases in İzmir province, KİDEM uses mortality data as the auxiliary source of data. The first

results of KİDEM were published in the European Journal of Cancer in 2001 under the title of “Incidence in Izmir in 1993–1994, first results from Izmir Cancer Registry (*Fidaner C et al., 2001*). The first population based survival rates were presented in the IARC Annual Scientific Meeting held in Uganda in 2005. (*Eser S et al., 2005*).

In addition to information such as name, surname, gender, date of birth, residence address and socio-demographical data headlines, date of diagnosis, valid diagnosis method as well as tumor-related headlines such as the topography, morphology, behavior, laterality and differentiation of the tumor that a population based center should collect, KİDEM also collects data on a very limited number of data headlines such as the stage and the last observation date. Upon considering the international recommendations, rules were established and are currently applied for the headlines of all collected data. ICD-O-3 is used in the classification and coding of the topography and morphology. Besides other auxiliary programs, basically Canreg-4 computer program is used to store and evaluate data. Canreg-4 is program that detects duplications and makes consistency controls among data headlines.

KİDEM became a member of WHO/IARC/IACR in 1995 and joined ENCR in 1997. Upon Turkey’s official membership in 2004, it was included in the Cancer Registry Project conducted within the framework of MECC. (www.mecc.cancer.gov).

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